Bath, North East Somerset, Swindon and Wiltshire (BSW) Integrated Care Board (ICB)

Position Statement on Joint Hypermobility and hypermobile Ehlers Danlos Syndrome (hEDS)

Updated August 2026

This position paper has been prepared by the BSW ICB Designated Medical Officer (DMO) and Designated Clinical Officers (DCOs) for Special Educational Needs and Disability (SEND) in response to an observed increase in the number of requests for joint hypermobility to be included in the health sections of Education, Health and Care Plans (EHCPs).

What is Joint Hypermobility

Joint hypermobility is a common, benign childhood condition. 'Hyper' simply means 'more' and 'mobility' means 'movement', therefore it describes joints that can extend beyond their normal range of movement. Ligaments offer stability to joints and when someone is hypermobile their ligaments are stretchier and joints have more flexibility.

Hypermobility is a common condition, with some studies suggesting that up to 71% of children under 8 years old and 55% of 4 to 14 year olds experience hypermobile joints (De Inocencio 2004).

Hypermobility is not an illness or a disease, and is considered a normal finding by medical professionals, especially in children who have not yet reached biological maturity.

The Beighton score is a nine point tool commonly used to assess joint hypermobility by measuring the flexibility of specific joints. It is not diagnostic and does not indicate a medical condition; as many individuals with high scores will experience no symptoms.

The Paediatric Physiotherapy Professional Leads within our commissioned children's community health provider have advised us that hypermobility should be 'normalised' and individuals should be encouraged to incorporate supportive strategies into their everyday activities of living to help manage their differences, recognising the mainstay of treatment is regular movement, to promote muscle strengthening and prevent

deconditioning, and analgesia, hot water bottles or ice packs when required to manage any pain and discomfort.

Hypermobile Ehlers Danlos Syndrome (hEDS)

Hypermobile Ehlers Danlos Syndrome (hEDS) is the most common subtype of Ehlers Danlos Syndrome (EDS) and is primarily characterised by joint hypermobility. However, unlike other EDS types which are rare, have a genetic cause, and often involve other organs for example vascular EDS, hypermobile EDS does not usually cause health needs.

Hypermobile EDS (hEDS) is usually diagnosed within primary care when an individual meets the 2017 international diagnostic criteria. However, we would not usually expect a diagnosis of hEDS to be given to a child (anyone under the age of 18) or anyone who has not yet reached skeletal maturity, because joint hypermobility is such a common childhood presentation and symptoms will often reduce with age. This position is supported by the paediatric diagnostic framework for joint hypermobility (2023) which classifies children with generalised joint hypermobility into eight subtypes based on joint, musculoskeletal, skin and comorbidity features, with hEDS being reserved for those aged over 18 or those who are skeletally mature.

In conclusion the ICB would not usually consider joint hypermobility to be a health need in relation to special educational needs. For these reasons it wouldn't need to be referenced in the health sections of an EHCP, recognising no specialist health or special education provision is required to manage this. Most supportive strategies will be focused on the home and education setting environment which can be delivered through reasonable adjustments, which are universally available to all children and young people.